

The Worst Thing

Tuesday, April 21, 2010, was the worst day of my life. My cell startled me from half-sleep at 6:03 a.m. I was dreading this call.

"Hello." It was my mother's surgeon telling me that the worst had come to pass and I had to meet him at the hospital as soon as possible to authorize him to perform a subtotal colectomy on my 56-year-old mother "in an attempt to save her life."

"I'll be right there," I said with tears streaming down my face. My brother came down the stairs. "Get dressed," I said. "We have to go to the hospital. Mom didn't improve overnight."

At the hospital, the surgeon ran through my mother's status. She was still septic and despite receiving huge doses of antibiotics and an experimental intravenous immunoglobulin treatment overnight, her vital signs were not stabilizing and surgery was our only option.

At 36, I was confronting the very grim possibility that my mother was going to die from a bacterial infection called *clostridium difficile*.

Circumstance

Despite having worked in the health care field in a variety of capacities (administrator, prospect researcher, fundraiser), I had never heard of *clostridium difficile* (or *C. diff*, as it's commonly known) until the previous day when I took my mother to a local hospital emergency room. Mom had been sick for about four days and in bed for much of that time with what everyone assumed was a stomach virus. Her predominant symptom was diarrhea.

She shared a two-family house with my younger brother, Liam, and his fiancée, Melissa. They looked in on her and brought her soup, water, Gatorade and other fluids. Since Mom was a kindergarten teacher, she assumed that she had picked up a stomach virus from one of her students. While Mom has always been a healthy and robust woman, being subjected to the germs of 24 five-year-olds resulted in her getting a head cold or stomach flu once or twice during the school year. These were always minor and it was unusual for her to take more than one sick day.

I spoke to Mom every day while she was sick, as was our habit. The Monday night before we took her to the hospital, I told her I was worried that she'd been sick for four days. She said she had spoken with her doctor on Saturday and then again that day and he had referred her to a gastroenterologist. We agreed that I would take her to the appointment the next morning. What we didn't put together was that earlier that week, Mom had been prescribed clindamycin following a routine dental procedure. She had been taking this powerful, broad spectrum antibiotic for several days when she became ill.

That Tuesday, I arrived at my mother's house around 11:30 a.m. My brother met me at the door and said Mom was taking a bath. We went upstairs together and Liam knocked on the door. A few seconds went by without an answer and we looked at each other nervously. "Mom?" Liam said again and banged a bit harder. She told us to come in and we both exhaled. Mom was laying in the bath, peering out at us from behind the shower curtain. "I wanted to get out of the tub but I feel weak and dizzy," she said. Covering her with a towel, Liam and I helped Mom out of the tub and into her bedroom so she could dress. I asked her if she felt strong enough to keep her appointment or if we should just go to the emergency room. She agreed that we should go the emergency room since she was very likely dehydrated and needed fluids. I asked if she wanted me to drive her or would she prefer we call an ambulance. She joked about having "great insurance" and told me to call one. While I was worried at this point that Mom was so dehydrated, I also thought that once we got her to the hospital and on an intravenous (IV) line of fluids, she would be fine.

Understanding

Things changed dramatically once the ambulance arrived. The paramedics found Mom's blood pressure dangerously low — from what we thought was the result of dehydration — and they needed to call for another ambulance with life support equipment. At the emergency room, the doctors determined that Mom had a massive infection, which they suspected to be caused by *clostridium difficile* and precipitated by the antibiotic. She was in shock and septic. They began fluid and antibiotic therapy. We were told she was profoundly ill, and her life was in jeopardy.

The doctors started a central line, performed additional blood tests and scheduled Mom for a CT scan. Following that, they performed a colonoscopy to determine if she had an obstruction. At this point, Mom was sedated and intubated. Following the procedures, the doctors told us that they were going to treat my mother with IV antibiotics and IV immunoglobulin overnight. If she didn't respond, they would perform a colectomy in the morning "in an attempt to save her life." We were told to go home and get some rest. If surgery was necessary, the surgeon would call us in the morning.

We went back to my brother's house because he lived closest to the hospital. Friends and family members stopped by to provide support, pray with us and assure us that our mother was a tough lady and would be fine. I searched the Internet obsessively trying to understand how my mother — a healthy, vibrant woman who had worked two jobs as long as I could remember — was near death from a bacterial infection. I learned that *clostridium difficile* is a gram-positive bacterium often responsible for causing diarrhea in hospital patients. In most cases, it is resolved with the use of additional antibiotics and, though about 20 percent of people will experience a relapse, had not generally been considered life-threatening. That had changed over the past decade. Throughout the 2000s, new strains of *C. diff* that were much deadlier were identified, first in Europe and Canada, and more recently in the United States. *C. diff* causes harm by producing a toxin that destroys the cells of the colon, leading to a condition called pseudomembranous colitis, which, in turn, can evolve into a life-threatening condition: toxic megacolon, wherein a person's colon is so overrun with both bacteria and toxin that it begins to necrotize. This is what happened to my mother.

Mom survived the surgery and was moved back to the intensive-care unit (ICU). Throughout the day, family and friends gathered and stood vigil. From late morning until the afternoon, it seemed that she was improving.

But around 4 p.m., her vital signs started to deteriorate. The doctors put her on 100 percent oxygen and provided additional drugs to support her blood pressure. Mom continued to decline throughout the afternoon. At 7:20 p.m., the ICU doctor informed us that my mother had gone into cardiac arrest. They had attempted to revive her three times, but to no avail.



Christian John Lillis



Response

The grief was epic. Not just for me and my family, but for our entire community. Our mother was a truly beloved figure in our neighborhood. She was one of nine children from an Irish, working-class family. When we were children, Mom worked as a waitress and put herself through college in pursuit of her goal of becoming a teacher. Throughout her many careers, Mom made innumerable friends. She had 12 godchildren. When we were teenagers, ours was the house with the "cool Mom" where all our friends congregated. As adults, our mother remained one of our closest confidantes and sounding boards, as she was for many other people in her life.

More than 500 people attended Mom's wake and funeral, and they all had the same question: "How does a healthy, 56-year-old woman die in five days from a disease no one has heard of?" In addition to the grief, the anger was palpable. Weeks after Mom had died, we continued to hear from people stunned to hear of her passing and full of rage that she taken from us so young.

I don't recall the exact conversation or series of conversations that resulted in our starting The Peggy Lillis Memorial Foundation. In addition to being a fundraiser and prospect researcher, I had long been an activist for gay rights, women's rights and HIV/AIDS causes. I knew, on some level beneath the grief, that anger of this magnitude among this many people could be channeled so that our mother's death would not be in vain.

Following the funeral, I began to research *C. diff* exhaustively. All the skills and knowledge I had gained as a prospect researcher were put to use assessing this silent epidemic. I learned that, minimally, 30,000 Americans die from *C. diff* infections every year. I say "minimally" because there is no national tracking system for *C. diff* the way there is for other infectious diseases with far smaller body counts. I learned that *C. diff* is largely preventable and that the primary vector for transmission is in health care settings. I learned that, though there are some organizations working on health care-associated infections (HAIs), there was no organization focused on *C. diff*, despite the fact it surpasses many other HAIs in terms of both prevalence and mortality. And the more I learned, the more enraged I became. And the more I shared with my brother, our family and my friends, the more enraged they became. So, about two months after my mother died, the vision for her memorial foundation had been established. We would raise awareness of this disease and advocate for better solutions in her memory.

Though I began my career in development as a prospect researcher and currently head the prospect research department of a national organization, I have worn many hats in the past 12 years: director of major gifts, director of development, event planner, board member and fundraising consultant. While I would need all of these skills, and the passion of our friends and family, I was convinced that together we could make an impact.

My mother had always told my brother and me that when she died, she didn't want us to mourn her death but to celebrate her life. With that in mind, we decided that our first big initiative would be to throw a fundraiser for our nascent foundation on what would have been our mother's 57th birthday, October 29, 2010. As anyone in development knows, planning a fundraiser in four months, while also putting together the infrastructure for our new nonprofit, is no easy task.

We began by getting our mother's siblings on board with both the foundation and the fundraiser. Then we put out a call to our family and friends for volunteers. The response was huge and we ended up with nearly 20 people working on the event committee. We began researching possible venues and found a local one where a family friend managed event contracts and was willing to give us a great deal. With volunteers on board, a venue and a date, we started building out our potential mailing list using a combination of prospect research and major gift strategies.

First, I took the guest book from Mom's wake and, using Anywho.com and Lexis-Nexis for Development Professionals, looked up addresses for those who left incomplete ones and cross-checked those that were hard to read until we had a tight mailing list. We then met with our family and Mom's close friends to review the list, identify who had strong relationships with our prospects, and gather information on those friends and acquaintances of who owned businesses or were otherwise more affluent. We then segmented the list accordingly.

Meanwhile, I worked on getting a fiscal sponsor for the foundation since we didn't have time to jump through all the legal hoops of creating a standalone 501(c)(3). Though I researched and contacted a number of potential sponsors, we ultimately engaged FJC: A Foundation of Philanthropic Funds. The staff at FJC was great — very empathic and happy to help launch the foundation. A family friend (actually, the daughter of my mother's godmother), who was very involved in raising money for the local public schools that her children attended, suggested that we hold a raffle and 50/50 at the fundraiser. Despite being in development for more than a decade, these techniques, primarily used with smaller community-based organizations, were relatively new to me. For the raffle, she suggested going to local businesses and asking them to donate products that we would gather into baskets with themes based on things Mom loved (learning, murder mysteries, Maui, etc.). More research followed as we worked to identify businesses that fit our themes and then who in our network knew the owners. We did a sponsorship mailing in July and then sent an invitation in early September.

On October 29, 2010, we held the first fundraiser for The Peggy Lillis Memorial Foundation called "Celebrating Peggy's Life." It was a runaway success. We had more than 275 guests and raised more than \$40,000. Friends put together a beautiful photo slideshow of Mom's life set to music she loved. My brother and I, as well as other of Mom's loved ones, shared our memories of her.

Liam and I also shared with guests our vision for The Peggy Lillis Memorial Foundation. We outlined the initial goals for the foundation:

- to build a comprehensive website for the foundation written by and for patients and loved ones;
- to assemble a National Advisory Council of traditional and holistic healthcare experts; and
- to produce a developing-focused brochure and producing the first-ever public service announcement about *C. diff*.



Growth

Having successfully held our first fundraiser and netted about \$20,000 to start the programmatic work of the foundation, we then moved on to building the website and recruiting for our National Advisory Council. What we initially learned about the dearth of patient-focused information remained true. Even the website of the Centers for Disease Control and Prevention contains outdated information regarding the presentation and treatment of *C. diff*. To ensure that our website would be both accurate and up-to-date, we conducted a great deal of research, synthesized that research and translated it into vernacular that the vast majority of Americans could understand. We were assisted in this effort by our advisers as well as friends and colleagues from throughout my career. The website launched in February 2011 and has quickly become the "go to" source for *C. diff* sufferers on the Internet. In August, the foundation had our first op-ed, "An epidemic that states have to stop," co-authored by Dr. Denice Hilty and me, published in the influential Albany Times Union.

Throughout the summer of 2011, we worked with a producer, Richard Davis, to produce the foundation's public service announcement (PSA). Again, through research and referrals, we identified leading doctors and public health experts, *C. diff* sufferers and families who had lost someone to *C. diff*. Our goal was to premiere the PSA at our second annual fundraiser, FIGHT C. DIFF, in October 2011. While producing the PSA, we also set about planning FIGHT C. DIFF. It was decided early on

that we needed to broaden the event's focus beyond Mom's story to incorporate an honoree and other people who had died or been harmed by *C. diff*. We also needed to broaden our base of financial support beyond the local community.

Using prospect research tactics, we identified an appropriate honoree, Dr. Sherwood Gorbach of Tufts University, who had been part of the research team that initially identified *C. diff* as a cause of what was then called "antibiotic associated diarrhea" in the 1970s. Dr. Gorbach had recently worked with a small, pharmaceutical startup, Optimer, to develop the first new treatment for *C. diff* in 25 years, *DIFICID*. I researched Optimer — its history, sales and philanthropy — as a potential sponsor. Using the knowledge gained through our research, I determined an appropriate solicitation amount, and we successfully cultivated and solicited Optimer. The company agreed to be the event's "Presenting Sponsor" with a gift of \$5,000, the foundation's largest single donation to date. FIGHT C. DIFF took place on October 22, 2011 and raised more than our first event while broadening the foundation's constituency. It was a significant achievement for the foundation and our cause.



Future

As of this writing, the foundation continues to grow in its reach and impact. We regularly receive calls and emails from *C. diff* sufferers and affected families who have lost a loved one to this quiet epidemic. They share their heartbreaking stories while commending our efforts. We are currently engaged in several efforts to advance the work of the foundation. We are cultivating a sponsor to underwrite the cost of distributing the PSA to television; planning our next fundraiser; building partnerships with other patient safety groups, such as the Consumers Union's Safe Patient Project and the Empowered Patient Coalition; and we recently started a blog.

Building a national movement to fight *C. diff* is going to be a marathon, not a sprint. Mom instilled in my brother and me great values and a fighting spirit, which we use in every aspect of our lives. From this grounding, we've begun our work since her death. The skills, tools and techniques that I learned as a prospect researcher and fundraiser have been indispensable in our efforts to leverage our mother's memory to save others. While nothing can bring my mother or the millions of other Americans who have been lost to *C. diff* back, the work of The Peggy Lillis Memorial Foundation is providing critical information and advocacy to help fight this epidemic.

Christian John Lillis is Managing Director of Research and Prospect Development at Teach For America, one of America's premiere education reform organizations. With more than 12 years of experience as both fundraiser and behind-the-scenes strategist for healthcare, LGBT rights and education organizations, he leads prospect identification and research programs that drive resource development both nationally and regionally.

*Christian is also Executive Director of The Peggy Lillis Memorial Foundation (PLMF), a volunteer-led educational organization, co-founded with his brother, Liam, following the death of their mother from a clostridium difficile (*C. diff*) infection in April 2010. PMLF works to increase prevention of and minimize death and disability resulting from *C. diff* infections by educating physicians, patients and the public at large, and by advocating for proven solutions within health care and public health systems.*

He holds a bachelor's degree in political theory from Brooklyn College, where he served as one term as President of the Lesbian, Gay, Bisexual and Transgender Alliance and won The Donald G. Whiteside Poetry Award his senior year.

Christian is a native of Brooklyn, New York, where he currently lives with his longtime boyfriend and their rescued "beagle baby," April. His hobbies include Tae Kwon Do (he is a Red 1 belt), reading comic books on his iPad, obsessing over JD Robb's "In Death" series, and playing Zombie Parkour on his iPhone.

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Thanks!

By: [Lori Hood Lawson, MLSc](#) | **Posted:** May 24, 2012 01:21 PM

Chrisitan, I just wanted to say thank you for sharing your story, and I commend you on bringing *C. diff* to the attention of the world. My heart goes out to you and your family!